Getting a Life

Findings
and Recommendations
from the

NASDDDS Invitational Symposium: State Strategies for Supporting Individuals with Co-Existing Conditions

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Additional copies of *Getting a Life* can be obtained from the NASDDDS Web site:
http://www.nasddds.org

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INTRODUCTION

In September 2004, the National Association of State Directors of Developmental Disabilities Services (NASDDDS) sponsored an invitational symposium to identify and discuss effective strategies for supporting individuals with developmental disabilities who additionally experience mental health and/or behavioral disorders. The meeting specifically addressed system-related issues that influence the provision of appropriate and effective services to individuals whose needs extend beyond the scope of traditional developmental disabilities (DD) community service systems. Participants included state officials and individuals with significant expertise in the design and implementation of support systems for individuals with co-existing conditions (see *Attachment* for a list of participants). The following key issues were addressed:

- Current Status and Trends. The strategies states currently employ to support individuals with co-existing conditions.

- Ideal Program Elements. Service-related "best" practices, policies, and procedures that are highly associated with positive outcome achievement – ***Objective 1.***

- Conceptual Model for Change. The changes that need to be made in existing service systems to incorporate best practices into the current regulatory, financing and operational frameworks of state/local DD and mental health (MH) service delivery systems – ***Objective 2.***

- Agenda for Change. Creation of a national research and program development agenda to guide efforts to improve state and local service delivery infrastructures – ***Objective 3.***

This paper reports on the outcomes of the symposium. The first section provides background information on the prevalence and etiology of mental illness and serious behavioral disorders among people with developmental disabilities. Section two summarizes the findings of a survey on state strategies for supporting individuals with co-existing conditions recently conducted by NASDDDS. This part also discusses the status of services, trends in support provision, and challenges currently facing state agencies. The essential elements of effective support interventions are described in the third section and the fourth recommends a course of action for integrating best practices into existing DD and MH service delivery systems. Section five details a national research and demonstration agenda for improving and expanding existing services. The document concludes with a summary of findings and recommendations.

BACKGROUND

Reports of the prevalence of mental illness (MI) among persons with developmental disabilities (DD) vary widely depending on a number of demographic, social, and psychological factors. Occurrence rates that have been cited in the literature range from 20% to 35% (Stark, 1989), depending on the characteristics of the population under review. Surveys of individuals

enrolled in community MR/DD programs have revealed incidence rates ranging between 10% and 40%, while large population studies report somewhat lower rates of 10% to 20% (Reiss, Goldberg & Ryan, 1993).

Researchers have posited several reasons for the increased rates of mental illness that appear among individuals with developmental disabilities. Bergman and Harris (1995), for example, suggested that individuals with developmental disabilities might be more apt to encounter the personal, emotional, and social stressors that are associated with mental illness than are members of the general population because of the nature of their intellectual disabilities. Ryan, in an article published in the Psychiatric Times,[1] emphasized the relationship between psychiatric and physiological problems, referencing research findings that 70% to 85% of individuals with developmental disabilities who are referred to a psychiatrist have at least one undiagnosed medical condition (Ryan and Sunada, 1997).[2] Other studies have suggested that 60% to 100% of individuals with developmental disabilities have histories of abuse and trauma (Sobsey, 1994)[3]. Still other investigators have suggested that mental illness occurrence rates may, in fact, be under reported due to diagnostic overshadowing – an evaluation bias reflecting a tendency of some clinicians to attribute symptoms of mental illness to an individual's co-existing diagnosis of mental retardation (Mason & Scior, 2004; Jopp & Keys, 2001; Sovner, 1986; Reiss, Levitan & Szyszko, 1982).[4]

Regardless of the etiology, it appears clear that individuals with developmental disabilities who have additional co-occurring diagnoses of mental illness or who demonstrate severe challenging behaviors are among the most difficult persons served by both the DD and MH service delivery systems. The problem does not stem from a lack of resources, although that is certainly an issue in some states. Rather, as reported in the recent NASDDDS survey of state officials, the barriers appear to be related to a lack of trained staff, insufficient or ineffective crisis intervention and support services, and the absence of appropriate clinical consultation and treatment.

Additional challenges exist in many states related to differences in state agency policy and practice governing eligibility, funding,

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[1] Ryan R. (December, 2001). Recognizing psychosis in nonverbal patients with developmental disabilities. *Psychiatric Times*. Vol. XVIII, Issue 12.

[2] Ryan, R.M., & Sunada, K. (1997) Medical evaluation of persons referred for psychiatric assessment. General Hospital Psychiatry 19(4):274-280.

[3] Sopsey, D. (1994). *Violence and abuse in the lives of people with disabilities: The end of silent acceptance?* Baltimore: P.H. Brookes Publishing Co.

[4] Mason J., and Scior K. (June 2004) 'Diagnostic overshadowing' amongst clinicians working with people with intellectual disabilities in the UK. *Journal of Applied Research in Intellectual Disabilities*: Vol. 17, Issue 2, p. 85.
Jopp, D. A., and Keys, C. B. (2001). Diagnostic overshadowing reviewed and reconsidered. *American Journal on Mental Retardation:* Vol. 106, No. 5, pp. 416–433.
Sovner R. (1986). Limiting factors in the use of DSM-III criteria with mentally ill/mentally retarded persons. *Psychopharmacology Bulletin*: Vol. 22, pp. 1055-1060.
Reiss S., Levitan G., & Szyszko J. (1982). Emotional disturbance and mental retardation: Diagnostic overshadowing. *American Journal on Mental Deficiency:* Vol. 86, pp. 567-574.

treatment, and professional service.[5] Symposium participants noted that state officials working to improve supports to individuals with dual diagnoses frequently need to dismantle or circumvent established policies and procedures in order to provide necessary and appropriate services. Perhaps the most intractable challenge is providing comprehensive treatment in a format that does not prevent the person receiving support from having friends and participating in work and community activities. Staff turnover and frequent changes in living environments causes social isolation and can make it impossible for individuals receiving support to experience the kind of enduring personal relationships that most people rely on to help them through the daily challenges of life.

EXPLORING THE ISSUES

Survey of States

In July 2004, NASDDDS surveyed member state agency officials on the strategies used to support individuals with co-existing developmental disabilities and mental illness, and/or intensive behavioral conditions.[6] The study gathered information on: (a) the distribution of responsibilities for funding and support provision between state DD and MH authorities, (b) the organization of crisis response services, (c) the key elements associated with effective service design and, (d) barriers to service delivery. The results of the survey underscored the complexity of the challenges states face when addressing the needs of individuals with co-existing conditions.

Achieving Positive Outcomes. The service-related decisions for individuals with co-existing conditions do not fundamentally differ from those made on behalf of other individuals with developmental disabilities and must address:

1. Eligibility.
2. Needs assessment.
3. Service planning and selection.
4. Service coordination.
5. Provider selection.
6. Funding
7. Evaluation and quality assessment.

The factor that distinguishes this group from others with developmental disabilities is the extent to which such decisions are influenced by the personal, emotional, behavioral, and medical needs of each individual concerned. People with co-existing conditions typically require more intensive support and supervision, staff with increased levels of skill and experience, professionals with specialized clinical expertise, comprehensive service coordination and monitoring, the presence of consistent back-up and support, and living arrangements that serve fewer people.

State officials reported that the program elements most directly associated with the achievement of positive outcomes

[5] For additional information see Fletcher, Beasley and Jacobson. (1999). Support service systems for people with dual diagnosis in the USA. In Bouras, N. (ed.), *Psychiatric and Behavioral Disorders in Developmental Disabilities and Mental Retardation*. Cambridge, UK: University Press (1999), pp. 373-390.

[6] The NASDDDS Technical Report, *Survey of State Strategies for Supporting Individuals with Co-Existing Conditions*, can be accessed from the Association's Web site at http://www.nasddds.org.

include: (a) the ability to individualize the services and supports offered to individuals with co-existing conditions, (b) the availability of effective systems for providing immediate support to persons in need of emergency assistance and, (c) the presence of effective methods of program planning and support coordination.

Barriers. Factors impeding states' efforts to furnish supports to individuals with co-existing conditions clustered around three major areas: service provider capacity, availability and willingness; the design and operation of the existing service delivery system; and the lack of funding designated to meet the needs of individuals with co-existing conditions.

Information Needs. State officials reported that their agency's efforts to address the needs of individuals with co-existing conditions were generally effective, but expressed little confidence that current approaches achieved all of the necessary outcomes. Throughout the survey, the respondents expressed the need for information on "best" or "promising" practices and program models that could be adapted to fit conditions in their own states. In particular, state officials expressed the need for research and demonstration initiatives addressing key areas of policy and practice including: (a) cost-effective alternatives for providing support and treatment, (b) strategies for training and workforce development, and (c) practical examples of successful crisis intervention models.

State officials reported that their efforts to support individuals with co-existing conditions would benefit most from information on the following topics (listed in declining order of importance):

- Funding issues, including cost containment, methods for increasing financial flexibility and targeting service dollars to individuals with co-existing conditions – 20 states.
- Best practice examples of effective service delivery models – 15 states.
- Best practice examples of effective treatment and clinical interventions – 13 states.
- Innovative approaches for training providers, direct support professionals and state officials – 13 states.
- Examples of cooperative interagency agreements and strategies for effectively coordinating services between and among state agencies and community providers – 10 states.
- The development of effective crisis response, coordination and prevention systems – 8 states.
- Information on diagnostic/assessment methodologies – 5 states.
- Innovative approaches for training clinical staff – 5 states.

Status and Trends

Symposium participants discussed the current context of service delivery and its impact on the provision of state financed services to individuals with co-existing conditions.

Current Status. The capacity of state developmental disabilities and mental

health agencies to develop and sustain services to individuals with co-existing conditions is being challenged by a number of factors. Human services are being reorganized in several states. Departments are being combined. Authority for policy development is becoming "homogenized," with responsibilities distributed among managerial units based on function rather than service population. In some states, the DD authority is being merged with state agencies responsible for supporting other populations including elder adults, persons with traumatic brain injury, and individuals with physical disabilities. Similarly, state mental health authorities are becoming integrated into health departments or combined with other state agencies. In many areas, these changes are accompanied by workforce reductions that strain state officials' capacity to remain focused on any particular group of high needs individuals.

State specific circumstances also may exert an impact on funding and service provision. Ohio officials, for example, reported that the need to treat a growing forensic population is expanding the department of correction's role in both DD and MH services. Currently, more than a quarter of all beds supported by the Ohio Department of Mental Health are designated for individuals involved in the criminal justice system. This proportion has grown from 12% to 27% over the past five years. Pressure to increase the number of forensic beds has placed demands on the mental health system, decreasing its capacity to support individuals with co-existing DD and MI who tend to use a disproportionately high number of bed days and services.

Increased service demand and an expanding need for interagency collaboration has strained the relationships between the developmental disability, mental health, and correctional authorities in several states. The recent NASDDDS survey (see discussion above) revealed that although the majority of state DD authorities report having effective working relationships with the state mental health agency, collaboration with state departments of corrections has been less successful. Symposium participants underscored the importance of interagency collaboration and the need for state agencies to work together in a unified approach to supporting individuals whose needs cut across programs and departmental boundaries. Participants noted that the establishment of *single point of entry* systems of intake, eligibility determination and service prioritization has enabled many states to clarify funding and program responsibilities between state agencies and take advantage of clinical and information technology.

Challenges and Barriers

The approaches state's employ to fund, treat, and provide long-term support to individuals with co-existing conditions vary, sometimes significantly, from one jurisdiction to another depending on the particular statutory and regulatory frameworks that apply. To provide common ground for the symposium discussions, vignettes of three hypothetical individuals with developmental disabilities were distributed to each participant. These brief descriptions provided information on each person's background, current status and specific problem or condition. One hypothetical individual was characterized by having a psychiatric diagnosis and

extensive but intermittent needs for clinical intervention requiring enhanced supports throughout the year. The second case scenario described an individual who demonstrated aggressive and criminal behavior that constituted a threat to the community. The third example portrayed an individual with mental illness who demonstrated severe aggressive behaviors.

Meeting participants from four states used these hypothetical cases to describe the paths that each person would take if he or she were to receive services from each of their respective states. Participants identified and discussed the structural, operational and attitudinal barriers that would be faced by the individual and state agency personnel in the development and implementation of the plan of care. Although the responses of each state official were different, the barriers they identified followed the same general themes relating to: (a) service system design and organization, (b) financing methodology, (c) service type and delivery and, (d) response to individual factors.

Design and Organization. State DD and MH agencies share many of the same treatment and support goals including community integration, self-sufficiency, independence, and the twin concepts of self-determination and recovery. But the systems tend to operate within separate ideological silos that can present significant barriers to active collaboration and joint service provision. State financed developmental disabilities programs, for example, are designed furnish services to a relatively stable group of individuals over their entire lifetimes, from "cradle to grave." Emphasis is placed on the provision of direct support to enable community access, training to develop the skills necessary to participate in community life and ancillary services to address health-related medical, therapeutic, and psycho-social needs. Mental health programs, by contrast, typically offer short-term treatment focusing on individuals' emotional or psychiatric needs and episodic support to assist in locating housing, employment, and community resources. The two groups operate through separate professional cultures and have differing system priorities and expectations regarding treatment and support.

Service organization is an additional barrier. DD and MH program authorities typically are organized to respond to the needs of eligible individuals who reside within set geographical "catchment" areas and meet specified qualifying criteria. It is frequently the case, however, that the areas of responsibility do not overlap making it difficult to coordinate services and funding. In Ohio, for example, the state DD system works through the 88 county governments which control funding and service provision. Mental health services, on the other hand, are not organized and delivered by county governments but rather are furnished through 50 county and multi-county community services boards and approximately 500 community mental health agencies.

States in transition need to develop a consensus on supporting individuals with co-existing conditions that will transcend the particular organization of the service system.

- Stan Butkus

Barriers also result from shifting political and administrative priorities within state

governments. State agency reorganization may alter the roles and duties of the agencies responsible for assuring service delivery. Significant functional changes can have a dramatic impact on the supports furnished to individuals whose needs extend beyond traditional service boundaries. Policymakers must be cognizant of the impact administrative restructuring will have on state agency's capacity to maintain the continuity of services provided to individuals with co-existing conditions.

Finance. Many people with co-existing developmental disabilities and mental illness have needs that overlap both systems and need to have full access to services regardless of the state agency responsible for funding. Yet, in many areas, significant barriers exist due to administrative and program requirements that tightly control access to services and provider reimbursement. Barriers to treatment may reflect: (a) conflicting funding methodologies, (b) funding availability and, (c) resource allocation issues.

- *Conflicting Funding Methodologies*. Inconsistencies in the funding methodologies employed by each state agency can present significant barriers to service delivery. In Ohio, for example, DD funding is individually based derived from a comprehensive person-centered plan and furnished by the county agency. MH funding, in contrast, is categorically based, organized by service type, and provided in set time segments as program related service units. A state official participating in the symposium noted that community mental health agencies in his state were reluctant to provide individuals with co-existing conditions more than the minimum supports that were determined to be necessary because current regulations cap the total number of hours that could be billed.

- *Funding Availability.* Access to services can be complicated further by the intensity of individuals' needs and the related high costs of service provision. Symposium participants noted that in many states, tight budgets and expenditure control requirements inhibit many state DD and MH authorities from working together to address the needs of individuals with co-existing conditions.

  Service access additionally is influenced by the lack of Medicaid funding for long-term support. Currently, long-term mental health care for individuals between the ages of 22 and 65 years may not be covered as a Medicaid State Plan service under Title XIX and cannot be funded under a Medicaid waiver because of the "IMD exclusion."[7] Home and community based services (HCBS) can, however, be furnished to individuals with developmental disabilities under a state's Medicaid 1915(c) HCBS waiver provided they meet intermediate care facility for the mentally retarded (ICF/MR) eligibility criteria. Because of the availability of federal matching funds (FFP), state developmental disabilities authorities are more apt to be given total responsibility for

[7] FFP is not available in expenditures for services provided to patients between the ages of 22 and 65 years who reside in an institution for mental diseases (IMD) [Title 42 CFR sec. 435.1008 (a)(2)]. As a result, there are no State Plan service requirements to waive.

funding and furnishing long-term support services to individuals with co-existing conditions.

- *Resource Allocation.* The support needs of individuals with co-existing conditions may be of a level of complexity that cannot be accommodated by existing cost allocation models. One symposium participant noted that DD authorities frequently lack effective procedures and tools for setting appropriate funding rates for individuals with complex and challenging needs. Further, many state agencies do not have mechanisms for increasing or decreasing rates to reflect changes in the person's life or needs over time. The result is that agency staff tend to overestimate the amount of staff time needed to serve such individuals.

Services. Symposium participants identified several barriers related to the access and delivery of the services, including the following:

- *Eligibility and Primary Diagnosis.* Fundamentally, state DD and MH systems are designed to serve individuals who meet specific eligibility criteria and to exclude those who do not. In many states service budgets are strained by increasing numbers of individuals requesting assistance and static or decreasing resources. Eligibility requirements may be designed to target resources to those most in need of support and assistance. As noted above, however, individuals with co-existing conditions frequently require services and supports from more than one state agency. Rather than increasing service availability, such targeting may actually prevent individuals with co-existing conditions from accessing the services and supports they need. Access to treatment can be further impaired by state policies that assign responsibility for funding and/or service provision according to a person's primary diagnosis.

  Ohio is one of several states that have taken administrative action to ensure that the person's primary diagnosis does not become a barrier to service provision.

- *Case Management/Support Coordination.*[8] The absence of effective case management and support coordination was identified as a significant barrier to the delivery and management of services to individuals with co-existing conditions. In many states there is no requirement that people with multiple conditions receiving support from more than one state agency have all services coordinated through a single entity. As a result, service recipients may have multiple service plans and case managers, each addressing the particular constellation of needs relevant to the state agency involved.

  Services are furnished according to the particular funding, eligibility, service provision, and monitoring standards of each agency and the differing

[8] For the purposes of this discussion the terms, case management and support coordination are used interchangeably to refer to the various activities involved in the development of individual program plans, service coordination, monitoring and community navigation. It is understood that in some areas the two terms have different meanings.

approaches may or may not successfully interface with each other. As a result, individuals with co-existing conditions who need to receive supports through stable, dependable and predictable environments must confront an ever-changing array of professional and direct support staff passing into and out of their lives. This separation of duties and responsibilities challenges the best efforts of each department to develop and maintain an integrated treatment approach.

If you have more than one case manager, you have too many.

- Steve Schroeder

In some states, excessively high caseloads make it virtually impossible for support coordinators to provide the level of assistance necessary to ensure effective service planning and coordination. In other areas, separate case managers and program plans are required for each category of service provided. An individual with co-existing developmental disabilities and mental illness who has committed an offense, for example, may have three case managers, one for each state agency involved. Rather than having too few professionals involved, consumers receive assistance from too many. In either case, the end result is a breakdown in service continuity and confusion over conflicting roles and responsibilities.

Problems with case management are not limited, however, to caseload size or the presence of too many case managers. Symposium participants expressed significant concern over the general quality of service coordination that is being provided nationwide. Indeed, one symposium participant opined that case management systems across the country are broken; caseloads are too large, training is inadequate and staff turnover occurs at such a high rate that program stability is impossible to maintain.

- *Service Separation*. In several states, individuals receiving services from more than one state agency have multiple treatment and support plans. Services are furnished in parallel fashion according to each state agency's requirements governing program planning, coordination, and service delivery. Programs are separated along lines that may or may not facilitate the person's growth and development. In this context it may be difficult, if not impossible, to develop a single treatment approach, combine funds or agree upon a single point of reference and accountability.

- *Service Availability and Access*. The availability of individuals with expertise in both developmental disabilities and mental health services was a major barrier identified by symposium participants. Access to services was said to be limited by a lack of psychiatrists, mental health practitioners, and direct support professionals with experience in providing positive behavioral supports. To improve access some states have adopted "single point of entry systems" for streamlining intake, treatment, and referral (see above). Others, in contrast, utilize a "no wrong door" approach that is designed to ensure that individuals quickly receive the supports they need regardless of

the circumstances under which they enter the service system.

The availability of emergency response or crisis intervention services was identified as a significant barrier to service provision. One participant noted that her state agency did not contract with service providers to maintain the capacity to meet the needs of individuals in crisis. To meet the need, "consultants" may be engaged to work with individual teams to assist in planning for the provision of appropriate back up supports.

- *Attitude.* Symposium participants agreed that the attitudes of professionals, staff, families, and the public at large present some of the most pervasive barriers to the development of effective supports systems for individuals with co-existing conditions. Several individuals observed that access to services was inhibited, for example, by psychiatric professionals who do not believe that persons with intellectual disabilities can benefit from therapy, clinicians who are not familiar with current treatment methods, administrators and legislators who believe individuals with co-existing conditions involved in the criminal justice system do not *deserve* costly community supports, and providers who refuse to support individuals with particular diagnoses.

Individual Factors. Symposium participants noted that a person's ability to benefit from treatment and support can significantly be influenced by individual factors related to the nature of the his or her condition, personal strengths and needs.

- *Communication Skills*. Data from the National Core Indicator (NCI) program revealed that 33% of all individuals with dual diagnoses surveyed did not speak or used augmentative communication aides.

- *Family Support*. NCI data additionally revealed that family members provided a significant amount of support and could continue to do so without "burning out" if they received assistance in the home.

- *Medical Conditions*. Dr. Ruth Ryan noted that practitioners needed to be aware of the medical and physical issues that may influence a person's behavior. She cited studies demonstrating that 75% to 100% of people who demonstrate aggressive or inappropriate behavior have undiagnosed medical conditions.

ESSENTIAL ELEMENTS OF EFFECTIVE INTERVENTIONS

The discussion of the essential components of effective service systems, ***Objective 2***, was led by presentations from five national experts (see *Attachment*); each presenter provided an analysis of key factors and support strategies influencing successful service outcomes. Programs and services that effectively address the needs of individuals with co-existing conditions are characterized by the following essential elements:

Leadership and Responsibility

Leadership in effective systems is "unambiguous," with clear lines of authority that establish single points of responsibility for decision making. Roles and duties are explicit and understood by

all parties: administrators, providers, clinical staff, direct support professionals, and individuals receiving support.

Persons in authority have the independence and support they need to make decisions that are in the best interest of the persons receiving services. Effective program administrators understand the state's organizational and operational culture. Staff responsible for service-related decisions are able to act in the best interest of the individuals receiving support and are protected from political pressures that can confuse the mission and objectives of the program.

Focus on the Individual

Services are individualized to fit the particular strengths and needs of each person being supported. Effective systems are structured at all levels to maintain a focus on what is important *to* the individual receiving support and what is important *for* the individual. Person-centered planning is implemented as an ongoing process, organizing service delivery to ensure the person's changing needs continue to be addressed. Person-centered planning processes are consistently applied across the state, backed by on-going training and support to staff, individuals receiving services, their families and others.

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*The person-centered planning process must determine what is important **to** the person and what is important **for** the person.*

- Michael Smull

Focusing on the individual means that state agencies serving individuals with co-existing conditions actively collaborate through a whole-person approach that enables each individual receiving support to "get a life" as a valued member of the community. Individuals are empowered and encouraged to take an active role in the decisions that affect their lives.

Focus on Staff

Symposium participants emphasized the important role direct support professionals play in both the design and delivery of services. Effective programs devote significant amounts of time and resources to staff recruitment, personnel selection, and training.

It's not a matter of showing up. It's who shows up. It must be someone with commitment and interest in the individual, someone who cares who is able to take a stand regarding what is best for the individual receiving support.

- David Pitonyak

Recruitment. Agencies, programs, and services that effectively address the needs of the individuals with co-existing conditions are characterized by their ability to hire staff whose interests and abilities match those of the person receiving support. The emphasis on human resource development extends beyond the need to ensure proper staff coverage throughout the work week. Recruitment activities are focused on locating people who have confidence in their own skills, a commitment to providing consistent support and broad knowledge of community resources.

Personnel Selection. The ability to achieve successful outcomes is most dependent on the quality of the relationships that exist between the individuals with disabilities

and the staff who provide them with direct support and ongoing assistance. The ability to achieve positive change in peoples' lives depends on skills of the person providing support and his or her attitudes regarding the individual and the job being performed. It was observed that policy is a "blunt instrument." Successful treatment and support outcomes depend on the people who are involved.

The critical challenge of supporting individuals with co-existing conditions is finding the right match between the person and the staff: the staff who perform direct support, the psychiatrist and other professionals at all levels who work with the individual.

- Ruth Ryan, M.D.

Effective service providers demonstrate a personal commitment to the individual, and believe in his or her ability to learn, change, and grow. Effective programs take the time to ensure that the right match exists between persons with disabilities and the staff who support them. Emphasis is placed on bringing together people who share the same interests, have had similar experiences, or just seem to like each other. Some staff are "naturals," able to communicate positive regard, acceptance and genuine caring for individuals with even the most intensive needs. Others, in contrast, appear to be unable to work effectively with individuals with challenging conditions, regardless of the training they receive. The difficulty lies in locating those individuals who are "naturals," and figuring out how they can transfer their skills to others.

Training. A central question for everyone, those with disabilities and those without, is, "whom can I depend on?" The chances of success are highest when people are supported by those individuals they trust and depend on the most. But how can you train a staff member to become dependable? Effective programs train staff to pay attention to the environmental issues that influence people's behavior; the physical and interpersonal factors that help the person feel safe, secure, and happy. Effective staff understand the nature of the relationships existing between the individuals receiving support and their friends, families and others who work with them. They know the people who are important to the individual and who should be called when the person is in trouble. Emphasis is placed on developing a sense of security by isolating those aspects of the person's life that stand in the way of his or her happiness and addressing each, one at a time.

The real question is how do you get the naturals to teach what they do?

- Chris Heimerl

Successful outcomes are more easily achieved when training is paired with clinical follow-up and treatment. In at least one state, the mental health authority provides training to developmental disabilities service providers in evidence-based treatment and the application of specific approaches such as dialectical behavioral therapy. Another state has established a virtual "Coordinating Center of Excellence" with contributions from the state mental health and developmental disabilities agencies, the state's developmental disabilities council and four in-state universities. The center's role is to provide training and technical support, and to assist in the development of community teams with the capacity to respond to the

needs of individuals with co-existing conditions throughout the state.

Focus on the System

Effective systems are characterized by the ability to learn from mistakes; to make program and policy decisions based on evidence, to change inappropriate or under-performing models, and to shift resources to support innovation. Additional characteristics include the following:

Individualization. Service systems are structured to encourage individualization and the flexible use of personnel and financial resources.

Collaboration. Systems work together to accomplish mutually held goals and objectives. State agencies invest time and effort in the development of productive, cooperative relationships, use common language, and share a commitment to successfully achieving the same individual and program outcomes. Program staff work to develop allies among other state agencies, local service providing organizations and individual professionals.

Systems need to have clarity of roles and purpose backed by a mutual sense of partnership and trust.

- Michael Smull

Capacity Building. State agency administrators demonstrate a commitment to the continued development and expansion of community service capacity over time. The focus is on building competencies within the "regular" developmental disabilities system to provide the clinical, diagnostic, treatment and long term supports that people with co-existing conditions need for successful community living.

Management. Effective systems are characterized by: (a) unambiguous leadership, (b) the presence of clear lines of authority and responsibility, and (c) the presence of operational protocols that assure decision makers have the autonomy, support and back-up they need to make key program decisions without unnecessary administrative review and approval.

Cross-System Training. Effective systems invest resources in cross-system training and technical assistance to ensure that staff possess skills in core competency areas.

Diagnosis and Treatment Planning. Systems have the capacity to perform comprehensive diagnostic assessments that address the psychiatric, medical, emotional, and social needs of the whole person.

Service Coordination. Planning for people with challenging needs is accomplished through a continuous process over time, rather than an event that occurs once each year. Case managers are able to work in the best interest of the people receiving support without conflicting employment responsibilities that limit or prescribe the options they are able to offer.

Data Keeping. Effective systems gather data on the outcomes individuals achieve, the barriers that are encountered, the costs incurred, and a wide range of other performance measures.

Housing. The context of service delivery is

changing reflecting an emerging consensus regarding the benefits of "shared living" as compared to traditional group settings. State agencies are increasing support provided to individuals living at home with their own families and expanding the use of less costly intensive foster care or shared living models that can be tailored to the needs of the individual.

Relationships are More Important than Events.

Throughout the discussion, the participants repeatedly stressed the critical role that personal relationships play in the achievement of successful individual outcomes. Chris Heimerl noted that service providers need to shift their focus from particular events (outbursts, behavioral episodes, etc.) to the activities that take place between the events that cause them to occur. Drawing upon his experiences with professionals from other disciplines, he noted the similarities between some of the key concepts associated with Chaos Theory in physics and the essential activities associated with successful human relationships. He noted that Chaos Theory seeks to identify and explain the order that exists in seemingly random events and suggested that the four laws of the universe as conceived by physicists may apply equally well to human services (see text box). Each state, for example, has one service delivery system which contains all of the resources that can be made available for the treatment and support of individuals with co-existing conditions within that jurisdiction. Each system is perceived differently by each of the various stakeholder groups and factions. Service options are improving with the benefit of increased experience and growing expertise and outcomes are expected to improve over time. "It is about relationships not events," Heimerl concluded, effective programs concentrate resources on the development and maintenance of long-term positive interpersonal relationships between the individuals receiving support and the staff who provide it.

The Four Laws of the Universe

1. There is only one universe and it contains everything.
2. There is only one universe and there many observers.
3. We will know more in the future.
4. It is about relationships not events.

- Chris Heimerl

Summary

Symposium participants agreed on the characteristics of effective systems of support for individuals with co-existing conditions. "Best" or "ideal" programs organize service delivery to address issues that are important *to* the person and are important *for* the person. Services demonstrating "best practice" are characterized by: (a) a focus on building strong interpersonal relationships that can develop into feelings of trust, dependability and predictability, (b) unambiguous leadership with clearly defined roles and responsibilities, (c) a designated single point of authority that has the responsibility and independence to make decisions that reflect the needs of the individuals receiving support rather than the program providing the support, (d) a focus on the individual and the capacity to tailor services and supports to meet the individual's needs, (e) active

training at all levels targeted to the needs of the individuals receiving support, and (f) a commitment to supporting the continued growth and development of the system over time.

MOVING FROM TYPICAL PRACTICE TO BEST PRACTICE

The Symposium's third objective was to outline a course of action for integrating innovative and best practice program elements into existing DD and MH service delivery systems. The participant's recommendations fell into three broad categories: leadership, collaboration, and performance improvement.

Leading Change

The ability to achieve successful program outcomes is highly dependent on the presence of leadership to motivate, direct, and sustain the process of change. Leadership is necessary to clarify the relationships and responsibilities of DD and MH authorities (as well as other state agencies), and to infuse appropriate values into all aspects of service design and implementation. The state agency must not only set the direction, mission and values of the initiative, but also must ensure the development of a coordinated process for integrating new and innovative services into the existing system.

The leadership that is required must be inclusive and encompass the activities of state policymakers, providers, direct support staff, individuals receiving support and their families. A key role of leadership is to develop and promote a realistic plan for change by providing a programmatic, fiscal, and ethical rational justifying the need for a new support paradigm. The rationale additionally should identify cost savings and program efficiencies that can be achieved by improving services to individuals with co-existing conditions.

Collaboration

Individuals with co-existing conditions require services and supports that typically extend beyond the capacity of the state developmental disabilities authority. Services frequently are provided through two or more state agencies, each with its own unique requirements governing eligibility, documentation, case management and program planning. The increased numbers of individuals and authorities involved necessitates that greater emphasis be placed on the development of positive working relationships between and among organizations. Symposium participants made the following recommendations regarding the collaborative efforts that need to take place to incorporate best practice into current DD and MH systems:

- Develop positive working relationships with both DD and MH advocates.

- Organize stakeholder work groups and advisory boards that involve people in productive problem solving activities and empower them to discuss and bring about change.

- Support approaches emphasizing the development of positive relationships and a sense of respect throughout the system from direct support staff to program director.

- Institute mechanisms that will ensure that policy makers and program administrators receive direct input, advice, and complaints from individuals receiving support, their families, and other interested parties.

Improving Performance on Key Program Activities

To improve performance, system managers need to develop mechanisms for tracking and evaluating changes that are made to the system to incorporate innovative and best practice support alternatives. The following suggestions were offered to system managers:

- Describe the outcomes to be achieved by the system change process. Identify key performance measures. Set performance criteria, gather data, assess the results, and document the outcomes achieved.

- Develop the capacity to gather information on the following: (a) the pattern of psychotropic usage; (b) the pattern of restraint usage; (c) changes in the institutional census and the conditions under which institutional services may be offered; (d) the perspectives of mid-level managers with respect to the provision of services to individuals with co-existing conditions; (e) the nature of the relationship between the DD and corrections authorities; (f) the number and pattern of deaths among people receiving services; (g) longitudinal data on cost, savings, benefits and best practice; and (h) the needs of individuals who are unable to be effectively supported by the current system.

- Provide focused training to enable staff to develop the skills and attitudes they need to effectively support individuals with co-existing conditions.

- Establish a decision tree or system of cascading "circuit breakers" for directing problematic issues to staff with the authority to take appropriate action.

- Develop the capacity of local programs and services to support individuals with challenging needs.

- Establish a mechanism for identifying people in crisis.

NATIONAL AGENDA FOR CHANGE

The final objective of the symposium was to identify the ingredients of a national research and program development agenda for improving the services offered to individuals with co-existing conditions. The agenda for change has two purposes: (a) to provide a guide for improving and expanding the capacities of existing state and local programs and, (b) to identify program related areas that are in need of additional examination, research and demonstration. Fundamentally, the scope and content of an agenda for research and demonstration must address two issues: the need for evidence, what state officials need to know; and the need for action, what state officials need to do.

Symposium participants agreed that research and demonstration projects related to the following areas would be of

significant value to states interested in improving the organization, financing, and delivery of services and supports to individuals with co-existing conditions.

- Needs Assessment. The methodologies and tools used by states to assess individuals service needs for support and treatment.

- Funding. Innovative and effective state practices for: (a) allocating resources, (b) developing individual budgets, (c) covering financial risk, (d) managing service-related costs over time and, (e) cost-effective service delivery approaches.

- Service Coordination. Effective strategies for: (a) collaborating with other state agencies and provider organizations, (b) sharing financial and human resources, (c) streamlining case management and program planning responsibilities, and (d) monitoring and evaluating service quality.

- Service Provision. Effective strategies for: (a) recruiting individual and agency providers, (b) developing expertise, and (c) increasing the willingness of existing providers to serve individuals with co-existing conditions.

- Training. Effective approaches for cross-disciplinary training, developing the expertise of existing clinicians, and building skills among direct support professionals.

- Collaboration. Effective models of collaboration and coordination between the state DD, MH, and Corrections authorities.

- System Change. Examples of system change initiatives successfully employed by states to improve services to individuals with co-existing conditions.

- Crisis Intervention/Emergency Response. Detailed information on the structure and functioning of crisis intervention and emergency response services that meet the needs of states with rural and dispersed population centers.

- Performance Evaluation and Assessment. Descriptions of effective data collection and management systems and examples of the use of data to document progress, evaluate individual and program outcomes and track key performance measures.

CONCLUSION

This paper reports the findings, recommendations, and conclusions reached by participants in the NASDDDS Invitational Symposium on State Strategies for Supporting Individuals with Co-existing Conditions. The document outlines the challenges states currently face in their efforts to design, develop and implement effective services for individuals with co-existing conditions, identifies the key policies and practices associated with effective programs, and recommends changes that need to be made in existing systems to incorporate best practice. An agenda for further research and investigation is included to inform further investigation of this topic.

Several themes ran through the discussions that took place during the September 2004 symposium, alternately emerging as

barriers to service provision, essential elements of effective service approaches, key operational capacities and areas in need of further analysis and study. Effective and ineffective programs are characterized by the presence or absence of the following:

1. A shared understanding of the roles and responsibilities of key staff, single points of responsibility and clearly identified lines of authority.

2. A focus on the needs of the individual receiving support, developing services on the basis of what is important *to* the person and what is important *for* the person.

3. A focus on the development of strong relationship between the person receiving support and the staff who provide it.

4. A focus on the staff, providing individuals with co-existing conditions with the training, support, and assistance they need to develop expertise, confidence, dependability, and predictability.

5. A focus on the development of core service capacities and decision-making procedures that support individuals with co-existing conditions at all levels.

6. A shared understanding of the essential role personal relationships play in the achievement of positive program and individual treatment outcomes.

7. A strong and continuing commitment to training.

Individuals with developmental disabilities who have co-existing serious mental health and/or behavioral conditions of an intensity that requires specialized or intensive services and supports comprise a relatively small proportion of the total number of persons served by state agencies. Yet, because of the complexity of their needs, they tend to require a significantly greater investment of staff time, professional expertise and financial resources than do the vast majority of persons supported by state and local developmental disabilities service delivery systems. Individuals with co-existing conditions frequently are eligible to receive (or may be required to receive) services through two or more state agencies and a complex network of local providers. The increased number of decision-makers and administrative jurisdictions involved in serving these individuals can significantly strain the capacities of each entity responsible for providing treatment and support.

The service related decisions that must be made regarding persons with co-existing conditions do not significantly differ from those required of all eligible individuals. Determinations must be made regarding eligibility, program planning, service coordination, service provider selection, funding, and quality assurance. The difference lies in the extent to which the responses to these considerations are overshadowed by the individual's co-existing mental health or behavioral condition. The complexity of their needs places demands on the expertise and capacity of the service system that far exceed the requirements associated with serving the majority of individuals receiving support.

The critical challenge facing state's efforts to address the needs of individuals with co-existing conditions lies in the development of effective strategies for incorporating "best practice" into existing state developmental disabilities service systems. From the perspective of the symposium's participants, successful system change initiatives would be characterized by the presence of unambiguous leadership, effective collaboration at all levels, and a commitment to improving performance on identified key outcome indicators.

Additional copies of this report can be obtained at
http://www.nasddds.org

NASDDDS Invitational Symposium: *State Strategies for Supporting Individuals with Co-Existing Conditions*

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